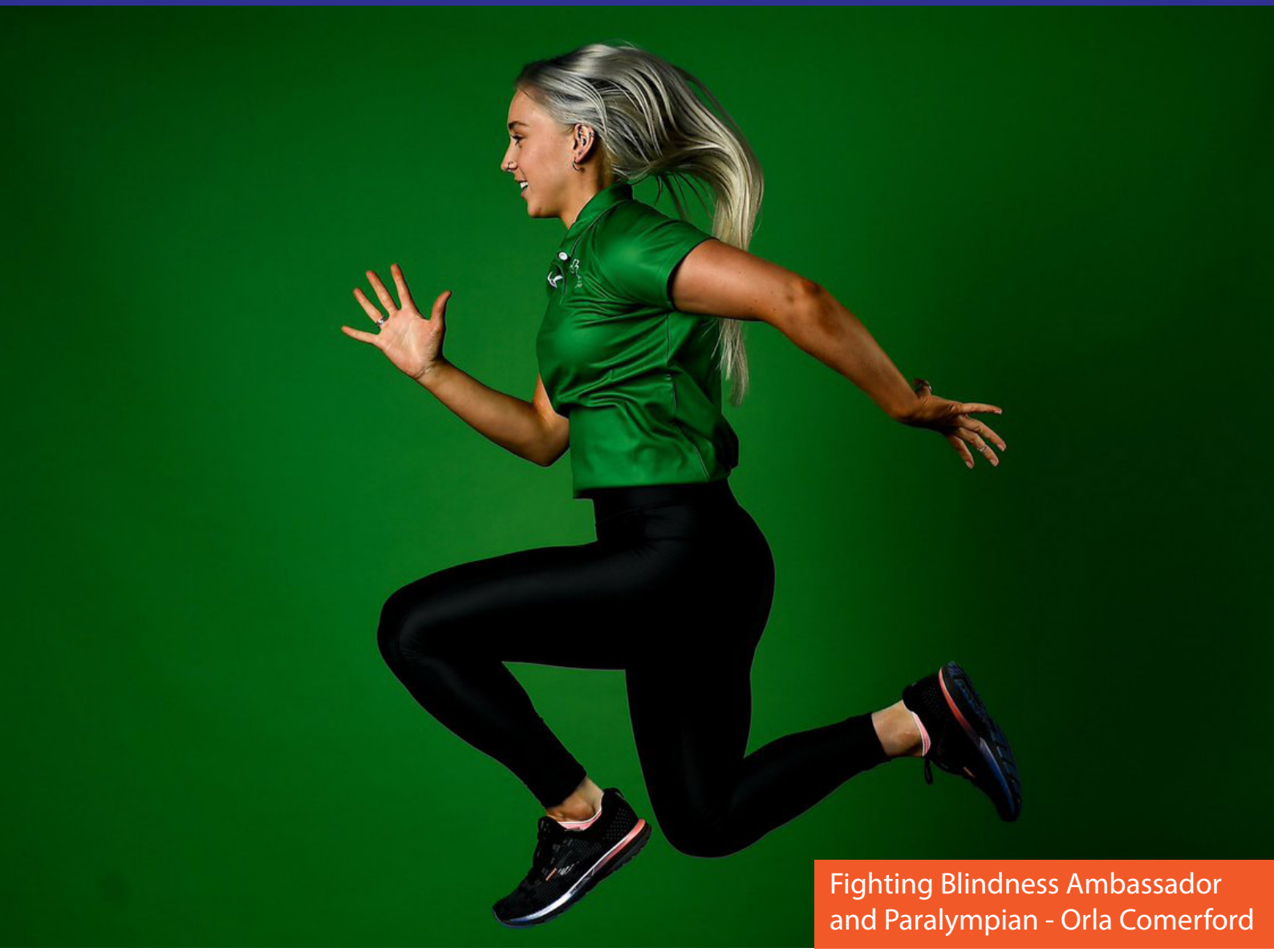
Visionaries

Fighting Blindness Newsletter | Autumn 2021



Fighting Blindness Ambassador and Paralympian - Orla Comerford

In this issue...

Register for Retina 2021

World Sight Day

FIGHTING BLINDNESS

Cure. Support. Empower.

Welcome

Dear members, supporters and friends,

I hope this newsletter finds you and yours healthy and safe.

As the pandemic has unfolded, we have all been faced with many challenges that have forced us to find new ways to adapt and perhaps rethink how we live our lives. That is also true of Fighting Blindness and we are continuing to innovate to research, support and advocate. Do not hesitate to contact us, as we will help in any way we can.

Faced with continued uncertainty, we have once again made the decision to host our annual Retina conference online. We will miss the opportunity to connect with you in person, but safety remains the priority. We will be providing support for those who require assistance with accessing the event through their digital device.

On Friday 5 November we will again be joined by the world's leading researchers and clinicians and the theme is gene therapy. A selection of speakers include Professor Brendan Buckley, Chairman Fighting Blindness, Michael Griffith, Founder Fighting Blindness, Dr. Christina Zeitz, INSERM, France and Dr. Orla Galvin, Retina International.

On the Public Engagement Day (Saturday 6 November) we'll welcome a selection of fantastic speakers including Breandan Ward, Ben Shaberman and Jake Ternent who was the first recipient of gene therapy Luxturna in the UK. Jake will tell us the impact of this treatment on his life. Head to our website to read the full agenda and book your free ticket. I look forward to seeing you all there.

We are calling on the HSE to reimburse the life-changing gene therapy, Luxturna. We have lobbied our political leaders throughout this year, and continue to ask officials at the Department of Health and HSE management to make this treatment available to those citizens who could have their sight loss stabilised or their vision improved by this treatment.

I'd like to take this opportunity to thank everyone who took part in or donated to our various fundraising initiatives over the past few months. With your continued support we have been able to commission further key research that is outlined on page 5. In addition to its4women and JCDecaux as our corporate sponsors we are also delighted to announce our partnership with Specsavers.

The outpouring of support and generosity – particularly during such a difficult time – is incredible.

From the Fighting Blindness team and our board – thank you.

Kindest regards,
Kevin Whelan
CEO

Retina 2021 – virtual Public Engagement Day

Most recent statistics show that there are almost 272,000 people living in Ireland with a vision impairment.

It's been an extremely difficult 18 months for the country, and this has perhaps been even more keenly felt by people with sight loss.

Living with sight loss comes with many challenges.

Unfortunately, COVID-19 has compounded these barriers, from navigating a socially-distant world, to attending hospital appointments, to accessing public services.

With that in mind, the forthcoming Retina 2021 Public Engagement Day, taking place on Saturday November 6 from 10am to 2pm, will focus on rebuilding resilience and optimism for the future among our community.

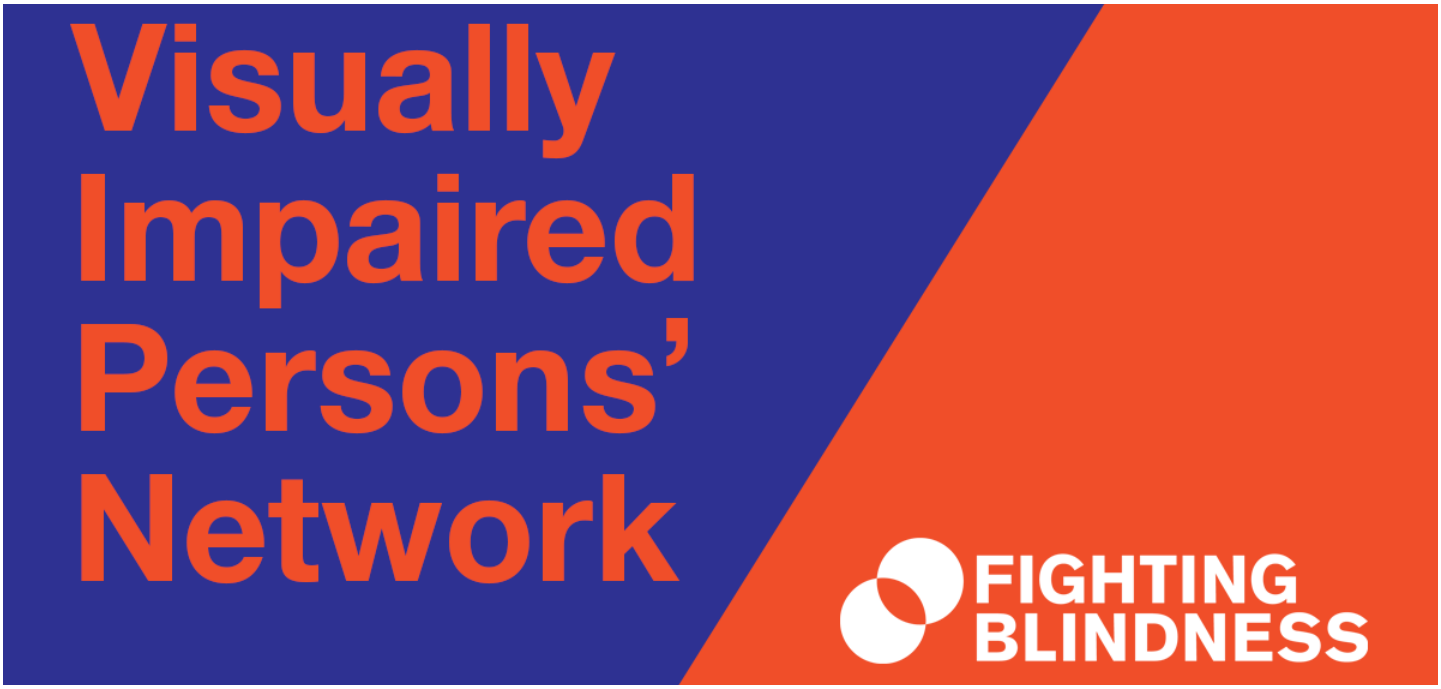
There will be presentations on the revolutionary developments taking place to retain and regain sight, as well as motivational talks on developing coping skills to ensure we live our best lives in the face of adversity.

There are indeed many reasons to be hopeful for what the next decade holds and this event aims to shine a spotlight on a very positive and encouraging future.

The conference is being presented virtually and registration is completely free on our website.

If you have any questions about the Public Engagement Day, please email communications@fightingblindness.ie or call 01 678 9004.

Are you interested in research and advocacy? Join the Fighting Blindness VIP (Visually Impaired Persons') network!



Have you heard of Fighting Blindness's VIP (Visually Impaired Persons') network yet? The VIP network is composed of visually impaired persons who are interested in becoming more involved in Patient and Public Involvement or PPI in research.

PPI describes how people living with medical conditions (patients) can become involved in research and advocacy activities. By working alongside scientists, clinicians, industry and/or regulators, the patient and their input can play an important role in contributing to and/or guiding the pathway to therapy development.

It is vital that the views and opinions of people living with sight loss are considered in all areas of vision research and advocacy. The goal of the VIP Network is to promote and facilitate meaningful engagement and involvement in research and advocacy and to help shape the work of Fighting Blindness.

Members of this group receive updates and invitations to participate in activities such as surveys, focus groups, training events, advice meetings, consultations and campaigns. Opportunities can range from reviewing applications made by scientists/clinicians, participating in focus groups for designing research studies to enrolling in patient education courses. Some opportunities may be more relevant to you than others and of course there is no requirement to become involved in any of the activities. People may want to join to only be kept up to date on what is happening.

Membership is open to people and families living with sight loss. To join or for more information please contact the Fighting Blindness Research Department on research@fightingblindness.ie or call 01 678 9004. We would love to have your input!

A new research project in the field of macular diseases

Professor Frans Cremers

In June 2021 a new 3-year project started that will be looking at macular diseases in more detail. The project is funded by Fighting Blindness and the Health Research Board. The lead researcher on the project is Professor Frans Cremers based in Radboud University Medical Center, in Nijmegen, the Netherlands. Professor Jane Farrar (Trinity College Dublin), Dr Susanne Roosing (Nijmegen) and Professor Anneke I. den Hollander (Nijmegen, Boston) are co-investigators on the project. The post-doctoral fellow Dr Rebekkah Hitti-Malin (in Nijmegen) and the PhD candidate Ms. Ella Kopcic (in Dublin) have started in this project.

In macular diseases (MDs) the center of the retina is not functioning correctly and thus affected persons experience difficulties with their central vision. Inherited MDs (iMDs), which can occur at an early age, are relatively rare and typically result in several decades of vision impairment. The more common age-related macular degeneration (AMD) generally affects the elderly. Although great progress has been made in identifying the underlying genetic factors for MDs, we still lack knowledge regarding genetic and non-genetic factors that underly MDs or influence the age at onset and severity of MDs.

We hypothesise that "inherited" and "age-related" MDs are not distinct diseases but form a scale with overlapping genetic and non-genetic factors. The overall objective of the project is to genetically characterize 1,000 persons with inherited macular degeneration (iMD), 1,000 persons with age related macular degeneration (AMD) and 1,000 control persons.

These studies should significantly increase the ability to diagnose MD cases which should identify individuals who may be eligible for novel therapies, and where appropriate, may aid people to make lifestyle and dietary changes, thereby improving long-term vision prospects. These studies will bring together an extensive network of clinical collaborators, scientists and patient groups to address this important group of diseases.

We look forward to seeing this research progress and hearing about the results!

A busy time for our support services

So far, 2021 has been an exceptionally busy year for our support service. The volume of individuals accessing Insight Counselling has been higher than the previous year and despite them still being delivered through Zoom, we are delighted to say that all of our various support and specific interest groups continue to flourish, with new members joining our mainstays all the time.

We recently added the 1000th person to our register of support service users. We've built on this record since 2002 and it's added to every day. In reviewing the expansion of our service recently, we found that in little over 2 years, we have supported 300 new individuals. It took 17 years of hard work to support the first 700, but it only took us 2 years to welcome the next 300. We hope you agree that this is quite an achievement!

We will endeavour to continue to be available and supportive for a wide range of people and to ensure that we are continually receptive and responsive to new clients and service users.

A number of surveys were sent on to participants late in the summer with a view of securing individualised feedback on people's opinions on how we can collectively move forward as restrictions hopefully lift as we enter the winter and 2022. We would like to extend our gratitude for all of the responses received and we appreciate the many words of encouragement sent our way.

> "The group took away my feeling of being isolated because of the pandemic."

As always, we need to acknowledge the dedication of our volunteers and to remind that every group is only as strong as its members!

The spirit of collaboration

One of the core foundations of our Support ethos is that we recognise that sometimes it is easier working with others than trying to go it alone. This of course applies to our individual lives but we'd also like to acknowledge the support and camaraderie we have experienced from by working with other organisations over the last few months.

We have benefitted from building stronger collaborations with NCBI with regards to developing our Counselling service. We also worked collaboratively with Irish Guide Dogs for the Blind on our pilot "Foundations" course for young adults. And of course, both organisations, alongside Sight & Sound Technology, Vision Sports, various doctors and Fighting Blindness volunteers have all contributed to our Living Well with Sight Loss Course. We are actively involved as governing members of Mental Health Reform, with whom we also regularly liaise.

Celebrating achievements

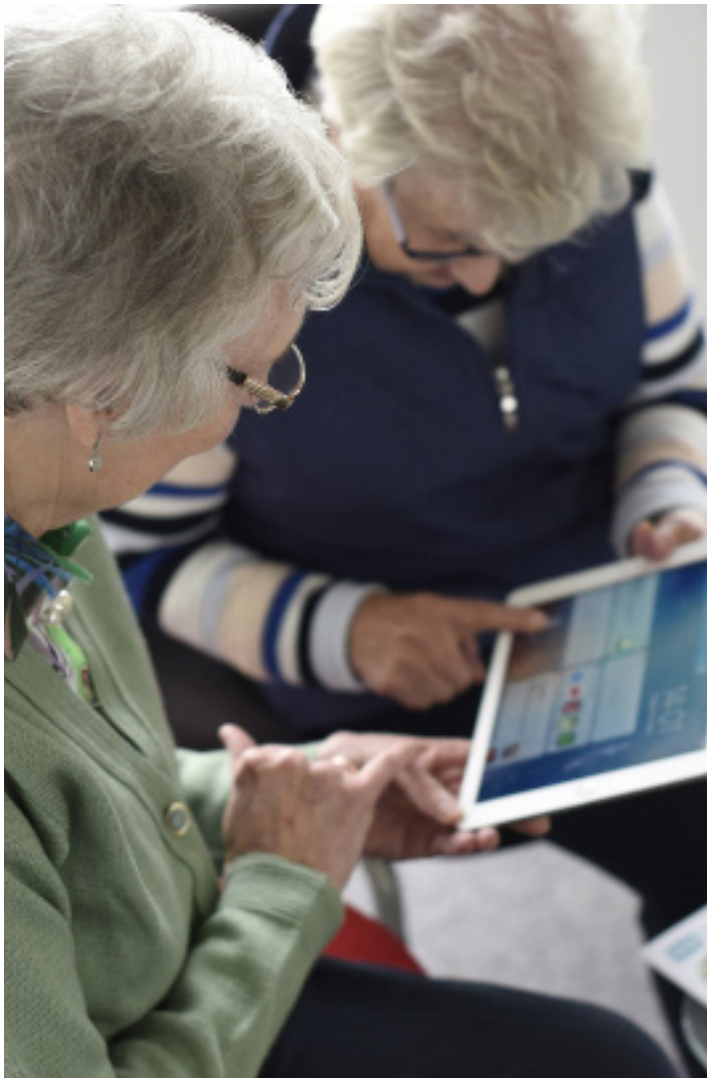
In the spirit of working with other organisations, our Support Service worked with the National Disability Authority to contribute to the launch of their report which reviewed the innovations and new practices that have emerged as a result of COVID-19. NDA felt that the increased services and the positive use of technology that Fighting Blindness had accomplished, really exemplified what can be done in spite of difficult circumstances. The video of the launch can be found here.

Many thanks to Marian, Stuart, Frank and Ken for their time and input!

Active connections

Our support service has been successful in receiving a small grant from the National Lottery to pilot a partnership on a new supportive venture. We aim to partner with Active Connections in 2022 with a view to offering opportunities for young people with visual impairments to participate in outdoor activity pursuits. This will initially be for participants in a few specific areas only and we'll share more details in time.

More information on Active Connections can be found here. We are excited about offering new opportunities to younger people and we hope this is the beginning of an enduring partnership.



“Directions” Peer Support Group for 18-30 year olds

“Directions” Peer Support Group for 18-30 year olds – Open to new participants!

Living with sight loss at a younger age can be difficult. Priorities relating to study, embarking on further education, job-seeking, securing independence and relationship difficulties can often be difficult to navigate and manage.

During these times, many people find it useful to talk through their feelings and experiences with someone outside their usual circle of family and friends. Vital support can often be found through meeting with others who have faced similar difficulties.

Our group has been meeting for a year now, once a month through Zoom – so no matter where you live, you’re welcome to join us!

If you’d like to have a chat about what’s involved, please call 01 674 6496 or email insight@fightingblindness.ie

World Sight Day 2021

The global event is celebrated the second Thursday in October and this year's message was 'Love your eyes'; to encourage people all around the world to take an eye test to protect their eyesight.

This year Fighting Blindness joined with sponsors Roche Pharmaceuticals Ireland to produce a series of videos with Fighting Blindness ambassadors Petrina Finn, Conor Lennon and Gillian Stafford who all told their stories. The public message being that sight loss is not binary but on a spectrum, and many people experience visual impairment differently.

Also, research helps us better understand vision impairment and this can lead to treatments and cures. Every small improvement or stability of vision is valuable.

These short films were shared across social media and are also available on our YouTube page.

Paralympian sprinter Orla Comerford joined Newstalk radio's The Pat Kenny Show on 14 October to spread the Fighting Blindness' message while double-gold Paralympian cyclist Katie-George Dunlevy alongside Conor Lennon and Gillian Stafford helped to spread the word in The Irish Times on 12 October.

Orla Comerford told listeners, "A key thing that people think when you are blind is that you are either fully-sighted or you see nothing; visual

Fighting Blindness member Conor Lennon

impairment is definitely something that is on a spectrum. There's a whole range of people in Ireland living with visual impairments that mean different levels of vision. I have quite poor central vision.

"Fighting Blindness is an Irish charity who do phenomenal work in research…and put in a huge amount to help people with visual impairments. They also do a lot to educate the public on their own eye health."

Also on World Sight Day, Fighting Blindness teamed up with sponsors Specsavers to launch a report on how Irish eye care has been affected by the pandemic entitled 'The State of Ireland's Eye Health 2021'.

The report highlighted that eye care services in Ireland were withdrawn, reduced or restricted in response to the pandemic. This led to thousands of missed eye tests, delays in treatment and extended waiting times for patients.

The campaign for reimbursement of Luxturna

Fighting Blindness has engaged with cabinet ministers, Department of Health officials and HSE management seeking reimbursement for Luxturna [Voretigene Neparvovec] that is made available to eligible citizens across western Europe – except Ireland and Switzerland. This gene therapy is the first effective treatment for the mutated RPE65 gene that causes sight loss for around five people in Ireland.

The initial letter to cabinet ministers outlined the key aspects of our interest in the reimbursement of Luxturna – including an emotional context for the children impacted by their loss of vision, but also addressing the budgetary implications for Best Supportive Care transferring from the Department of Health to the Departments of Education, Finance and Social Protection. The second layer of correspondence included the infographic on how Ireland is out of step with the majority of western Europe.

James Kennedy from Malahide in Dublin featured on the RTÉ Radio One Today with Claire Byrne show, in an interview recorded on 25 August and broadcast on 30 August. Fighting Blindness was mentioned twice in the 9 min 30 sec interview – which was uploaded to the RTÉ website with the title 'Fighting Blindness'. The Irish media has started to show interest in this process for the reimbursement of 'orphan drugs'.

Separately, The Times [Ireland] noticed from Fighting Blindness' lobbying return that we had contacted a series of designated public officials – and the follow-up story was published online on 4 September with the headline 'HSE deliberates on wonder-drug to cure blindness'.

Jake Ternent, the first person to be treated with Luxturna in the UK, and James Kennedy who hopes to be treated in Ireland soon will both be speaking about their experiences at the Public Engagement Day for Retina 2021 on Saturday November 6.

An autumn of exciting fundraising partnerships!

Fighting Blindness ambassador Greta Streimikyte

As we move into the autumn months, our acting Fundraising Manager Kathryn Sinnott is excited to share some news about existing and new partnerships.

We're proud to once more be chosen as a Charity of Choice for 2021 - 2022 by JCDecaux who will provide us with free nationwide outdoor advertising space. A new billboard campaign will roll out across the country in early 2022.

We are also delighted to announce that Specsavers have chosen Fighting Blindness as their Charity of Choice. We look forward to engaging with this new partnership.

We are grateful as ever for those of you who have raised much needed funds for Fighting Blindness. We have been amazed and incredibly touched by the generosity of our donors who have ensured our services have continued to grow and expand. Thank you.

Thank you to all who participated in our virtual Steps4Sight event! A special thank you to our top fundraisers Elizabeth and Roisin O'Donnell who raised a whopping €1,995!

Specsavers

"Save my sight change my life"

Please support the Rotunda RetCam Appeal

"I don't have regrets and things happen for a reason. But I do think 'What if the hospital had a RetCam when I was a premature baby?' Everything may have turned out a bit differently."

-Greta Streimikyte, Irish Paralympian

Please scan here to donate

FIGHTING BLINDNESS

Reg Charity No 20013349

THE ROTUNDA FOUNDATION

Reg Charity No 20079529

An Autumn Soirée with Victoria Smurfit and Evie Baxter

Victoria Smurfit

Evie Baxter

Enda Kenny

Our classical concert performed by Meadhbh O'Rourke and Friends also proved to be a great success. Former Miss Ireland Holly Carpenter is currently undertaking a golf challenge which will continue into 2022. These events have raised an amazing €10,000.

Congratulations to Stephen Surdival and his tandem partner Suzie King who took part in the epic Paris to Nice cycle challenge in aid of Fighting Blindness. Suzie has a visual impairment, and this was a fantastic achievement.

Recently, we celebrated the work of Fighting Blindness in London at Bentley's Restaurant in Mayfair.

We would like to thank Victoria Smurfit and her daughter Evie and all those who attended for helping to create such a magical and memorable evening.

In 2022, the Glendalough Trail Run and the Vision Walk in Marbella will return. We also have plans for a fantastic Fashion Show and virtual Rowing challenge from Skibbereen to Botany Bay!

If you would like any advice on setting up your own fundraiser, you can find some tips on our website www.fightingblindness.ie or call us on 01 678 9004. You can also email fundraising@fightingblindness.ie.

Encouraging our strong ethos of engagement with members

Dear Members, Friends and Supporters,

I hope you are well. As the pandemic has unfolded we have all been faced with many challenges that have forced us to find new ways to adapt and perhaps rethink how we live our lives.

The trustees of Fighting Blindness want to ensure that the organisation continues its strong ethos of engagement with our members, to address any possible improvements that our members and supporters have identified. To this end, the trustees would like to host a series of safe and productive meetings where ideas can be openly discussed in a friendly and cooperative manner.

Data protection prevents individual trustees making direct contact with our members on such issues, so we would like to cordially invite you to register your interest in making contact to participate in a future Zoom meeting with a nominated trustee. It is envisaged that each meeting will be a group of around six to eight people.

Our core values have remained as: Cure. Support. Empower. Our primary focus has been to finance academic research into sight loss to speed up finding cures and treatments to the spectrum of conditions. As we progress with this, there is always a need to support our community to live their best lives. We are also committed to empower our community through advocacy and organisation to ensure that our voice is heard and that we can influence public policy and public opinion to improve lives.

If you would like to participate in this open consultation, we will furnish you with the contact details of your randomly nominated trustee to cordially arrange a meeting. It is expected that meetings will be held throughout the early part of November 2021.

If you would like to take part in shaping Fighting Blindness
please email contact@fightingblindness.ie and we will revert to you as soon as possible.

Yours sincerely,

Kevin Whelan
CEO

Our vision is to cure blindness, support people living with sight loss and empower patients.

Fighting Blindness
Tel: 01 678 9004
Email: info@fightingblindness.ie

www.FightingBlindness.ie
Charity No: 20013349